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Quality of Life Measurement in Neurodegenerative and Related Condition

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## Preface

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Patient-reported outcome measures (PROMs) are now generally regarded as central to the evaluation of health and medical care. This represents a substantial change in opinion from that of just a few decades ago, when the systematic collection of patient reports of their health and quality of life was a relatively new area of research. Today, PROMs feature in routine data collection systems and are seen as important in the monitoring of health care provision. They are increasingly used as primary outcomes measures in trials. Thus, the measurement of quality of life, or what is sometimes referred to as health-related quality of life, has moved into the mainstream of evaluation. In part, this reflects the growth in “patient-centered care,” and the importance now placed on public and patient views of health care. Thus, health care must reflect the needs of patients, and assessment of services must reflect both “consumer” views and “patient-reported outcomes.” This text is evidence of this move toward patient-centered evaluation and documents the development and validation of quality-of-life measures for use in a wide variety of neurodegenerative, and related, conditions. This book is primarily concerned with the development, validation, and application of disease-specific measures. Such instruments are generally regarded as potentially more precise and sensitive to changes than more generic measures because they are intended to reflect the particular demands of specific conditions.

The first chapter documents established methods for the development and validation of instruments

and introduces readers unfamiliar with the area to the fundamental concepts of measurement in quality-of-life measurement. The following chapters document the current state of the art in measurement of Parkinson's disease, multiple sclerosis, motor neuron disease, progressive supranuclear palsy, multiple system atrophy, Huntington's disease, and dementia. The particular demands of measuring the health status of children are explored in the chapter on cerebral palsy. Although cerebral palsy is not a neurodegenerative disorder in itself, the impact of the condition on growth for children, and on aging for adults, often causes, over time, profound changes in functioning and health status.

Consequently, the phenotype of cerebral palsy has been referred to as a "progressive neuromuscular" condition\* – hence its inclusion here. The impact of serious illness can have substantial effects on family members and friends, and these issues are explored in a chapter on quality of life and carers. The final chapters of the book explore methodologic issues in translation and scoring of instruments, as well as the place of more individualized measures that are specifically designed to reflect the concerns of individual patients. This book is intended to give a clear idea of the range of instruments available, as well as the issues involved in their development, validation, and application.

\* Graham HK. Painful hip dislocation in cerebral palsy. *Lancet* 2002; 359: 907–908.